

# FAIR Equivalency with Regulatory Framework for Digital Health in Uganda

Mariam Basajja<sup>1†</sup>, Mirjam Van Reisen<sup>1,2,3</sup>, Francisca Oladipo<sup>4</sup>

<sup>1</sup>Leiden University, Leiden, 1011NC, Amsterdam, the Netherlands

<sup>2</sup>Leiden University Medical Centre (LUMC), Leiden University, 1310 Leiden, the Netherlands

<sup>3</sup>Tilburg University, P.O. Box 90153 5000, the Netherlands

<sup>4</sup>Federal University, 260101 Lokoja, Nigeria

**Keywords:** eHealth; Digital health; GAIR Guidelines; FAIR Equivalency; Findable; Accessible; Interoperable; Reusable; HMIS

Citation: Basajja, M., Van Reisen, M., Oladipo, F.: FAIR Equivalency with regulatory framework for digital health in Uganda. *Data Intelligence* 4(4), 771–797 (2022). doi: 10.1162/dint\_a\_00170

Submitted: March 10, 2021; Revised: June 10, 2022; Accepted: July 15, 2022

---

## ABSTRACT

This study explores the possibility of opening a policy window for the adoption of the FAIR Guidelines—that data be Findable, Accessible, Interoperable, and Reusable (FAIR)—in Uganda’s eHealth sector. Although the FAIR Guidelines were not mentioned in any of the policy documents relevant to Uganda’s eHealth sector, the study found that 83% of the documents mentioned FAIR Equivalent efforts, such as the adoption of the National Identification Number (NIN) as a unique identifier in Uganda’s national Electronic Health Management Information System (eHMIS) (findability), the planned/ongoing integration of various information systems (interoperability), and the alignment of various projects with international best practices/standards (reusability). A FAIR Equivalency Score (FE-Score), devised in this study as an aggregate score of the mention of the equivalent of FAIR facets in the policy documents, showed that the documents at the core of Uganda’s digital health/eHealth policy have the highest score of all the documents analysed, indicating that there is a degree of alignment between Uganda’s National eHealth Vision and the FAIR Guidelines. Therefore, it can be concluded that favourable conditions exist for the adoption and implementation of the FAIR Guidelines in Uganda’s eHealth sector. Hence, it is recommended that the FAIR community adopt a capacity building strategy through organisations with a worldwide mandate, such as the World Health Organization, to promote the adoption of the FAIR Guidelines as part of international best practices.

---

<sup>†</sup> Corresponding author: Mariam Basajja, Leiden University (Email: mariam.basajja@gmail.com; ORCID: 0000-0001-7710-8843).

### ACRONYMS

|          |  |
|----------|--|
| DHIS     | District Health Information Software             |
| EAC      | East African Community                           |
| EAHRC    | East African Health Research Commission          |
| eHMIS    | Electronic Health Management Information System  |
| FAIR     | Findable, Accessible, Interoperable, Reusable    |
| FE-Score | FAIR Equivalency Score                           |
| HMIS     | health management information system             |
| ICT      | information and communication technology         |
| NDP      | National Development Plan                        |
| NIN      | National Identification Number                   |
| NITA-U   | National Information Technology Authority—Uganda |
| OpenMRS  | Open Medical Records Systems                     |
| VODAN    | Virus Outbreak Data Network                      |

---

## 1. INTRODUCTION

### 1.1 Background

Since the dawn of the Internet, rapid technological advances have made it possible for anyone to generate data. This ‘Big Data’ deluge has resulted in a multitude of separate data sets that exist as siloes. This data, which is stored in diverse data repositories, is, to a large extent, neither discoverable nor accessible by humans or automated means, greatly hindering knowledge, discovery and innovation. Hence, in its current state, the contemporary digital ecosystem hampers data discovery and reuse, preventing the maximum benefit from being derived from data resources [1]. In order to address this problem, science funders, publishers and government agencies are beginning to require data management and stewardship plans for data generated by publicly-funded projects, including in relation to data collection, annotation, archiving and long-term care [1].

In 2014, a group of academics, industry leaders, funding agencies, and scholarly publishers came together and championed a set of guidelines called the FAIR Guidelines, which were designed to support good data management by making data and metadata easily discoverable by both humans and machines [1]. The four components of these guidelines are that data be ‘Findable’, ‘Accessible’, ‘Interoperable’, and ‘Reusable’ (FAIR) [2]. When data is not FAIR, it becomes difficult to carry out the deep and broadly integrative analysis that is usually required to answer a research question. It can often take weeks (or months) to gather the necessary data. Considering the rapidly growing and evolving data environment, with new technologies, and new and more complex data types and formats constantly being developed, it is more important than ever that data is machine-actionable/readable. The harmonisation and integration of the data deposited in general-purpose and special-purpose repositories (making such data FAIR) will go a long way towards extracting maximum benefit from data, saving time and significantly reducing the cost of doing research [1].

The FAIR Guidelines were constituted in Europe by a small group of interested stakeholders calling for the ‘FAIRification’ of data and services in the life sciences [1]. They rapidly gained support among major players, such as the European Union, G7, G20 and US-based Big Data to Knowledge (BD2K). In 2017, the European Union established the European Open Science Cloud (EOSC). In addition, the European Commission decided that all publicly-funded scientific research from 2020 onwards is required to progressively introduce FAIR-based data stewardship in all research domains [3, 4].

Since its inception in 2014, FAIR uptake has seen considerable progress in some parts of the world [4]. In Africa, the main instances of FAIR implementation have been in the area of digital healthcare [5, 6]. Van Reisen and others argued that FAIR has the potential to address structural problems in healthcare in Africa—such as the lack of sustainability of digital health initiatives and fragmentation and lack of integration of health service solutions—as long as the principles are adopted and implemented with contextual awareness [5]. The adoption of FAIR in Africa is, therefore, very important. However, despite the obvious benefits accruing from FAIR implementation in Africa, its uptake has been slow [5].

The first case study of integrating FAIR Guidelines in digital health in Africa was the establishment of the East Africa Open Science Cloud for Health (EAOSCH) by the East African Community (EAC) in 2019 [5]. The main purpose of this regional data initiative is to support the sharing of health data across EAC member states. This initiative will demonstrate the advantages of data reuse and interoperability across borders [5]. To set common and shared standards for digital health that enable cross-border healthcare across the EAC region, the East African Health Research Commission (EAHRC) aims to develop and promote regional principles for data sharing (e.g., based on the FAIR Guidelines and shared cloud services, etc.), system interoperability, and digital tool design [5].

### **1.2 Main Study Objective**

This study was conducted under the GO FAIR Implementation Network Africa [7] and the Virus Outbreak Data Network (VODAN) [8], as part of a project that aims to develop a FAIR Data Point for Uganda [9]. It looked at the extent to which conditions (health data policies and documents) in the digital health/eHealth ecosystem in Uganda allow for the opening of a policy window for the adoption and implementation of the FAIR Guidelines and how these guidelines solve the challenges faced by the eHealth sector in Uganda.

### **1.3 Specific Study Research Question and Objectives**

In order to assess the governance framework for digital health/eHealth policy in Uganda and explore the possibility of a policy window opening for the FAIR Guidelines to be adopted in Uganda’s eHealth sector, the main research question was: *To what extent and in what way is the lack of policy on data management, data sharing and data analytics contributing to the lack of sustainable digital health solutions in Uganda?*

The objectives of this study were to:

- Understand the governance framework for digital health/eHealth in Uganda as well as standards for digital health data
- Investigate the conditions in the digital health/eHealth ecosystem in Uganda and evaluate the possibility of a policy window opening for the adoption and implementation of the FAIR Guidelines

This first objective was achieved by studying the governance framework for digital health/eHealth policy in Uganda from both a health policy perspective and an information and communication technology (ICT) data management perspective, with particular emphasis on digital health data. To achieve the second objective, emphasis was placed on reviewing key policy documents regarding digital health/eHealth governance in Uganda and assessing the context within which FAIR would have to be introduced to maximise the chances of its adoption.

## **2. MATERIALS AND METHODS**

### ***2.1 Theoretical Considerations***

Kingdon identified that new ideas can enter the policy agenda when the problem, potential policy solutions and political relevance pertaining to the problem are aligned. At such a point of alignment a policy window opens, which is a specific moment in time, when a new idea can enter the policy agenda [10]. The dynamic process that Kingdon describes, allows for the investigation of how policy changes and the role of policymakers and other policy entrepreneurs, who are ‘members’ of policy networks in a certain domain [10, 11]. Van Reisen and others explain that the discrepancy between the FAIR Guidelines and the opinions and beliefs of researchers and practitioners who are expected to use these Guidelines can be considered cultural entropy [4]. The authors go on to argue that if cultural entropy is large, it will hinder the acceptance of the FAIR Guidelines, as it is likely to result in a discrepancy in terms of what is perceived as the problem and what the solution could be [4].

### ***2.2 Study Design***

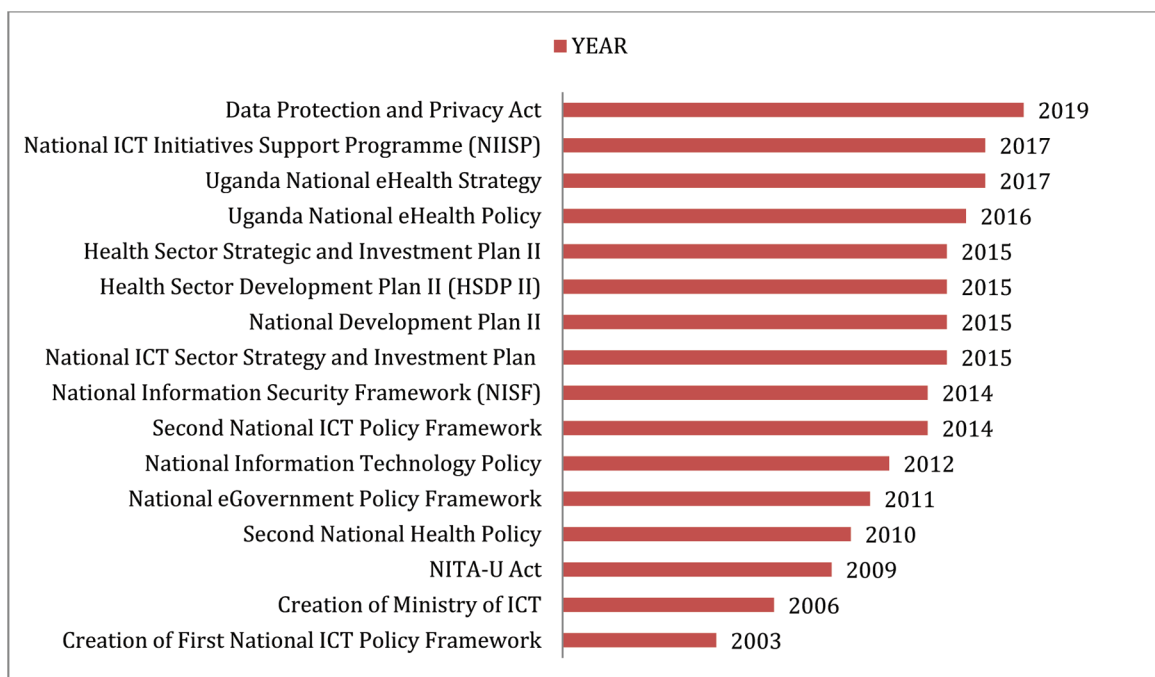
This study was a qualitative cross-sectional study that involved analysing both ICT-related and health-related policy documents published by the Government of Uganda between 2009 and 2019.

### ***2.3 Evolution of ICT and Health-Related Policies in Uganda—Historical Perspective***

In order to identify which policy documents and legislation are the basis for digital health/eHealth policy in Uganda, the history of ICT and health-related policies in Uganda was investigated. The year 2000 marked the beginning of implementation of key ICT and health sector reforms in Uganda [12]. In order to understand the prevailing conditions in the digital health/eHealth sector in Uganda, an exploration of the health policies and ICT policies that have been established since then was undertaken, with a focus on the steps that resulted in the final promulgation of eHealth reforms in Uganda.

In the early 2000s, the Government of Uganda realised that there were new issues emerging due to the Internet and the rapid changes in technology. To address these new trends, the government approved the National ICT Policy Framework in 2003 to guide the development of the ICT sector in Uganda. In order to harmonise the different aspects of ICT scattered in different ministries, the Ministry of ICT was created in 2006 in order to bring all aspects of ICT under one roof [13]. To provide further guidance to the ICT sector, a number of policies have been put in place (Figure 1), including the:

- National Information Technology Authority Act (2009), which led to the creation of the National Information Technology Authority-Uganda (NITA-U)
- National e-Government Policy Framework (2011)
- National Information Technology Policy (2012)
- National ICT Policy Framework (2014)
- National Information Security Framework (2014)
- National ICT Sector Strategy and Investment Plan (2015)
- National ICT Initiatives Support Program (2017)
- Data Protection and Privacy Act (2019)



**Figure 1.** Timeline of the formulation of ICT, health and related policies in Uganda since 2000.  
Source: Created by M. Basajja, 2021

The National ICT Policy, which was launched in 2014, states that due to the dynamic nature of the ICT sector, a number of areas have emerged that necessitate the government's policy pronouncement. Among these areas is eHealth [13]. Subsequently, the Ministry of Health developed policies regarding eHealth. These included a draft National eHealth Policy (2013) and a draft National eHealth Strategy (2013), which subsequently gave birth to the National eHealth Policy (2016) [14] and the National eHealth Strategy (2017) [15]. These were meant to guide the use of ICT in supporting health sector transformation, because the Ministry recognised the potential of ICT to transform healthcare delivery by enabling information access and supporting healthcare operations, management, and decision making [14].

#### **2.4 Uganda's National eHealth Vision**

An investigation into the extent to which the conditions in the digital health/eHealth ecosystem in Uganda allow for the opening of a policy window for the adoption and implementation of the FAIR Guidelines was undertaken to understand the governance framework of the digital health/eHealth sector in Uganda. As mentioned above, the eHealth sector in Uganda was launched by the publication of the National eHealth Policy (2016) [14] and, subsequently, the National eHealth Strategy (2017) [15]. The Government of Uganda, through the Ministry of Health, identified 13 priority areas, which it called pillars, on which emphasis must be placed in order to realise the National eHealth Vision (Figure 2). These pillars were promulgated in the National eHealth Policy and the National eHealth Strategy. A leadership and governance framework has been assigned for the implementation of each pillar, along with an action plan and five-year timeframe in which it should be done [15].



**Figure 2.** The 13 eHealth pillars in Uganda's National eHealth Vision [14].

Each of the 13 pillars was assigned a budget and an action plan for the five-year period (2016/17–2020/21). For each pillar, the strategic objectives and associated strategic initiatives were designed to be implemented in three phases: Phase I (2016/17–2017/18); Phase II (2018/19–2019/20) and Phase III (2020/21).

### **2.5 Identification of Relevant Documents**

A total of 14 documents, including plans, policies/policy frameworks, acts (of parliament), strategies and programmes (here and thereafter referred to as ‘policy documents’), were identified as relevant to the research objectives in this study (see Table 1). These policy documents are ICT/health-related and published by the Government of Uganda. Some of the documents were obtained from ICT personnel in the Ministry of Health and others from the websites of relevant government institutions, as shown in Table 1. Two relevant documents, the Health Sector Strategic and Investment Plan II (2015/16–2019/20) and the National ICT Sector Strategy and Investment Plan (2015/16–2019/20), were excluded because they could not be found on the Internet and were not provided upon request. The remaining 12 documents were included in the analysis, covering the period 2009 to 2019 (according to their publication date). This approach is similar to the one used by Mutatina and others in their scoping review of Uganda-specific health policy and systems-relevant documents, which involved five steps: identification of the research question; identification of relevant documents; screening and selection of the documents; charting of the data; and collating, summarising and reporting results [16].

### **2.6 Mention of the FAIR Guidelines in Policy Documents**

To find out whether or not the FAIR Guidelines are mentioned in the policy documents selected as relevant to the eHealth sector in Uganda (Table 1), the documents were analysed using the coding and labelling method to see if they explicitly (or implicitly) mention the components of the FAIR Guidelines (Findable, Accessible, Interoperable and Reusable). In order to support a wide range of special circumstances, the FAIR Guidelines were intentionally designed to be minimally defined, concise, high-level principles [1]. In the 2016 paper that first described the principles, the authors were very brief in their explanations [1]. The GO FAIR website was used to obtain a more detailed explanation of the principles in order to accurately interpret them during the analysis of the policy documents [2, 17].

After a comprehensive review of the policy documents, it was discovered that the FAIR Guidelines, as published in the FAIR foundational article by Wilkinson and colleagues in 2016 [1], are not mentioned in any of the policy documents analysed. However, certain terms (single words) or phrases (statements) that are semantically similar to the FAIR Guidelines have been used in the policy documents and, therefore, show a similar policy direction. For example, keywords such as integrate, harmonise, coordinate, incorporate, collaborate, one stop centre, common systems, common infrastructure, shared services, information exchange, alignment, open-source, and common language/vocabulary all relate to ‘Interoperability’. The term ‘FAIR Equivalent’ was, therefore, coined to describe such terms and statements.

**Table 1.** Policy documents analysed.

| SN | Title   | Type of document | Year | Publisher                                 | Source of document  |
|----|---|------------------|------|---|---|
| 1  | National Information Technology Authority-Uganda (NITA-U) Act | Act              | 2009 | National Information Technology Authority | <a href="https://www.nita.go.ug/sites/default/files/publications/NITA-U%20Act%20%28Act%20No.%204%20of%202009%29.pdf">https://www.nita.go.ug/sites/default/files/publications/NITA-U%20Act%20%28Act%20No.%204%20of%202009%29.pdf</a>   |
| 2  | Second National Health Policy                                 | Policy           | 2010 | Ministry of Health                        | <a href="http://library.health.go.ug/sites/default/files/resources/Second%20National%20Health%20Policy%202010.pdf">http://library.health.go.ug/sites/default/files/resources/Second%20National%20Health%20Policy%202010.pdf</a>   |
| 3  | National eGovernment Policy Framework                         | Framework        | 2011 | Ministry of ICT                           | <a href="http://www.ict.go.ug/wp-content/uploads/2018/06/National_E-Government_Policy_Framework_2011-2.pdf">http://www.ict.go.ug/wp-content/uploads/2018/06/National_E-Government_Policy_Framework_2011-2.pdf</a>   |
| 4  | National Information Technology Policy                        | Policy           | 2012 | Ministry of ICT                           | <a href="https://www.unodc.org/res/cld/lessons-learned/uga/information-technology-policy-for-uganda_html/NATIONAL_IT_POLICY_2012_1_1.pdf">https://www.unodc.org/res/cld/lessons-learned/uga/information-technology-policy-for-uganda_html/NATIONAL_IT_POLICY_2012_1_1.pdf</a> |
| 5  | National ICT Policy Framework                                 | Framework        | 2014 | Ministry of ICT                           | <a href="https://ict.go.ug/wp-content/uploads/2018/11/ICT_Policy_2014.pdf">https://ict.go.ug/wp-content/uploads/2018/11/ICT_Policy_2014.pdf</a>   |
| 6  | National Information Security Framework                       | Framework        | 2014 | National Information Technology Authority | <a href="https://www.nita.go.ug/sites/default/files/publications/National%20Information%20Security%20Policy%20v1.0_0.pdf">https://www.nita.go.ug/sites/default/files/publications/National%20Information%20Security%20Policy%20v1.0_0.pdf</a>                                 |
| 7  | Second National Development Plan                              | Plan             | 2015 | National Planning Authority               | <a href="http://npa.go.ug/wp-content/uploads/NDPII-Final.pdf">http://npa.go.ug/wp-content/uploads/NDPII-Final.pdf</a>   |
| 8  | Second Health Sector Development Plan                         | Plan             | 2015 | Ministry of Health                        | <a href="http://health.go.ug/sites/default/files/Health%20Sector%20Development%20Plan%202015-16_2019-20.pdf">http://health.go.ug/sites/default/files/Health%20Sector%20Development%20Plan%202015-16_2019-20.pdf</a>   |
| 9  | Uganda National eHealth Policy                                | Policy           | 2016 | Ministry of Health                        | <a href="http://library.health.go.ug/download/file/fid/517">http://library.health.go.ug/download/file/fid/517</a>   |
| 10 | Uganda National eHealth Strategy                              | Strategy         | 2017 | Ministry of Health                        | <a href="http://health.go.ug/sites/default/files/National%20e_Health%20Strategy_0.pdf">http://health.go.ug/sites/default/files/National%20e_Health%20Strategy_0.pdf</a>   |
| 11 | National ICT Initiatives Support Program                      | Program          | 2017 | Ministry of ICT                           | <a href="https://ict.go.ug/wp-content/uploads/2019/06/NIISP-Program.pdf">https://ict.go.ug/wp-content/uploads/2019/06/NIISP-Program.pdf</a>   |
| 12 | Data Protection and Privacy Act                               | Act              | 2019 | Ministry of ICT                           | <a href="https://ict.go.ug/wp-content/uploads/2019/03/Data-Protection-and-Privacy-Act-2019.pdf">https://ict.go.ug/wp-content/uploads/2019/03/Data-Protection-and-Privacy-Act-2019.pdf</a>   |

Source: Compiled from various sources by M. Basajja, 2021



Whether or not a statement contained in the policy documents is equivalent to the FAIR Guidelines was ascertained based on whether or not it carries the same intent/purpose or meaning as the one provided by the original FAIR article [1]. For example, where the documents advocate for the use of standards with the intent/purpose of enabling data exchange, the specific statement was labelled as equivalent to the FAIR Guideline of ‘Reusability’, which requires that data and metadata meet domain-relevant community standards. Statements in the policy documents were labelled by appending the initials of the FAIR Guidelines that they represent, i.e., ‘F’, ‘A’, ‘I’, or ‘R’ (Supplementary Material Basajja, 2021). The policy documents were arranged in rows. ‘FAIR Mention’ and ‘FAIR Equivalent’ were listed in two columns and annotations were tabulated using a binary code system: ‘1’ was assigned to the FAIR Mention or FAIR Equivalent column in cases where the policy documents mentioned either the FAIR Guidelines or their equivalent (FAIR Equivalent), whereas ‘0’ was assigned in cases where neither of the two were mentioned (see Table 2 in Results). This spreadsheet approach is similar to the framework method, an increasingly popular approach to the management and analysis of qualitative data in health research [18–20].

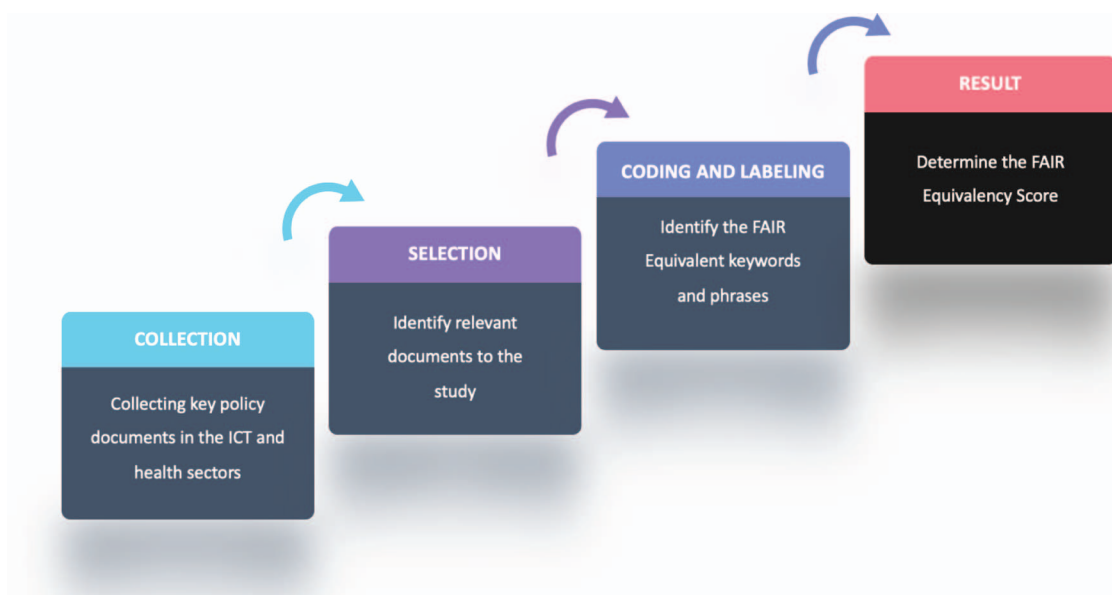


Figure 3. Process of determining the FAIR Equivalency Score in policy documents in Uganda. Source: Created by M. Basajja, 2021

### 2.7 Level of FAIR Equivalency in Policy Documents

In order to understand the level of FAIR Equivalency in the policy documents analysed, the analysis was extended to indicate which of the equivalent of the 15 sub-criteria of the FAIR Guidelines (hereafter, referred to as ‘FAIR facets’) are mentioned in the policy documents. These FAIR facets comprise the following: ‘Findability’ (F1, F2, F3, F4); ‘Accessibility’ (A1, A1.1, A1.2, A2); ‘Interoperability’ (I1, I2, I3) and ‘Reusability’ (R1, R1.1, R1.2, R1.3) [1].

The facets of the FAIR Guidelines are:

- To be 'Findable':
  - F1: (meta)data are assigned a globally unique and persistent identifier
  - F2: data are described with rich metadata (defined by R1 below)
  - F3: metadata clearly and explicitly include the identifier of the data it describes
  - F4: (meta)data are registered or indexed in a searchable resource
- To be 'Accessible':
  - A1: (meta)data are retrievable by their identifier using a standardised communications protocol
    - A1.1: the protocol is open, free, and universally implementable
    - A1.2: the protocol allows for an authentication and authorisation procedure, where necessary
  - A2: metadata are accessible, even when the data are no longer available
- To be 'Interoperable':
  - I1: (meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation.
  - I2: (meta)data use vocabularies that follow FAIR Guidelines
  - I3: (meta)data include qualified references to other (meta)data
- To be 'Reusable':
  - R1: meta(data) are richly described with a plurality of accurate and relevant attributes
    - R1.1: (meta)data are released with a clear and accessible data usage licence
    - R1.2: (meta)data are associated with detailed provenance
    - R1.3: (meta)data meet domain-relevant community standards

A detailed and comprehensive analysis of the mention of the equivalent of the 15 FAIR facets in each of the policy documents was carried out and organised by codes (the text) and labels (the 15 FAIR facets) [18]. In this analysis, the mention of the equivalent of the FAIR facets in the policy documents was labelled by appending the appropriate FAIR facet (i.e., F1, F2, F3, F4; A1, A1.1, A1.2, A2; I1, I2, I3; R1, R1.1, R1.2, R1.3) to the corresponding statements (Supplementary Material 2 Basajja, 2021). The policy documents were arranged in rows while the FAIR facets were arranged in columns. For each policy document, the mention of the equivalent of the FAIR facet was scored '1', while the lack of mention of the equivalent of the FAIR facet was scored '0' in the corresponding data cell of the Microsoft Excel spreadsheet (see Table 3 in Results). From this data, the FAIR Equivalency Score (FE-Score) was calculated by aggregating the scores across all the 15 facets per policy document. Hence, the highest possible FE-Score for each policy document is 15 (Supplementary Material 3, Basajja, 2021).

### 3. RESULTS

#### 3.1 Mention of FAIR Guidelines in Policy Documents

The analysis of whether or not the policy documents mention the FAIR Guidelines found that although none of the documents specifically mention the FAIR Guidelines, 10 out of the 12 documents (83%) mention the equivalent of the FAIR Guidelines (see Table 2). Only two documents do not mention any

aspects that relate to the FAIR Guidelines. This means that 80% of the documents relate to FAIR Guidelines to some extent. The documents that do not pertain in any way to FAIR Guidelines are from 2009 and 2012, so these are relatively early policy documents.

**Table 2.** Coding and labelling of whether FAIR Guidelines or FAIR Equivalent were mentioned ('1') or not ('0') in policy documents analysed.

| Policy document                                 | FAIR Mention | FAIR-Equivalent |
|---|--------------|-----------------|
| NITA-U Act (2009)                               | 0            | 0               |
| Second National Health Policy (2010)            | 0            | 1               |
| National eGovernment Policy Framework (2011)    | 0            | 1               |
| National Information Technology Policy (2012)   | 0            | 0               |
| National ICT Policy Framework (2014)            | 0            | 1               |
| National Information Security Framework (2014)  | 0            | 1               |
| Second National Development Plan (2015)         | 0            | 1               |
| Second Health Sector Development Plan (2015)    | 0            | 1               |
| Uganda National eHealth Policy (2016)           | 0            | 1               |
| Uganda National eHealth Strategy (2017)         | 0            | 1               |
| National ICT Initiatives Support Program (2017) | 0            | 1               |
| Data Protection and Privacy Act (2019)          | 0            | 1               |
| Average   | 0            | 0.833333333     |
| Percent   | 0%           | 83%             |
| Sum of FAIR-Equivalent (n)                      | 0            | 10              |

Source: Created by M. Basajja, 2021

### 3.2 FAIR Equivalency in Policy Documents

The FAIR Guidelines [1] consist of 15 FAIR facets. Upon finding that 83% of the policy documents analysed mention the equivalent of the FAIR Guidelines (FAIR Equivalent) (Table 2), a detailed analysis was conducted of which of the 15 facets were equivalently mentioned in each policy document. The policy documents were carefully reviewed for use of equivalent terms to: 'Findability' (F1, F2, F3, F4); 'Accessibility' (A1, A1.1, A1.2, A2); 'Interoperability' (I1, I2, I3); and 'Reusability' (R1, R1.1, R1.2, R1.3).

The results of the analysis are as follows (in descending order, starting with the most mentioned): A1 (75%, n=9); I1 (66.7%, n=8); A1.2 (58.3%, n=7); A1.1, R1.3 (50%, n=6); F1 (41.7%, n=5); F4, I3, R1, R1.1, R1.2 (33.3%, n=4); F2 (25%, n=3); I2 (8%, n=1); A2, F3 (0%, n=0) (Table 3). Across all documents, the most mentioned FAIR Equivalent facets (A1, I1 and A1.2) are mentioned in 9, 8 and 7 documents, respectively, out of the 12 documents. The least mentioned FAIR Equivalent facets were I2, which is mentioned in only one document (8%), and F3 and A2, which were not mentioned in any of the documents (0%). These results are plotted in clustered bar graphs in Figures 5a, 5b, 5c and 5d.

In general, 'Accessibility' (A=A1+A1.1+A1.2+A2) facets are the most frequently mentioned with a sum of 22, followed by 'Reusability' (R=R1+R1.1+R1.2+R1.3) with a sum of 18. 'Findability' (F=F1+F2+F3+F4), which has a sum of 12, and 'Interoperability' (I=I1+I2+I3), which has a sum of 13, feature less often.

In order to determine if the policy documents become more FAIR Equivalent over time, a score called the FAIR Equivalent Score (FE-Score) was calculated. The FE-Score is an aggregate score of the mention of the equivalent of the FAIR facets/sub-criteria in all the policy documents. Each mention of any of the 15 FAIR facets/sub-criteria was scored '1', while no mention of the sub-criteria was scored '0' across all documents. The FE-Score was obtained by aggregating the scores for each of the 15 sub-criteria per policy document, with the highest possible score being 15 (Table 3 and Figure 4).

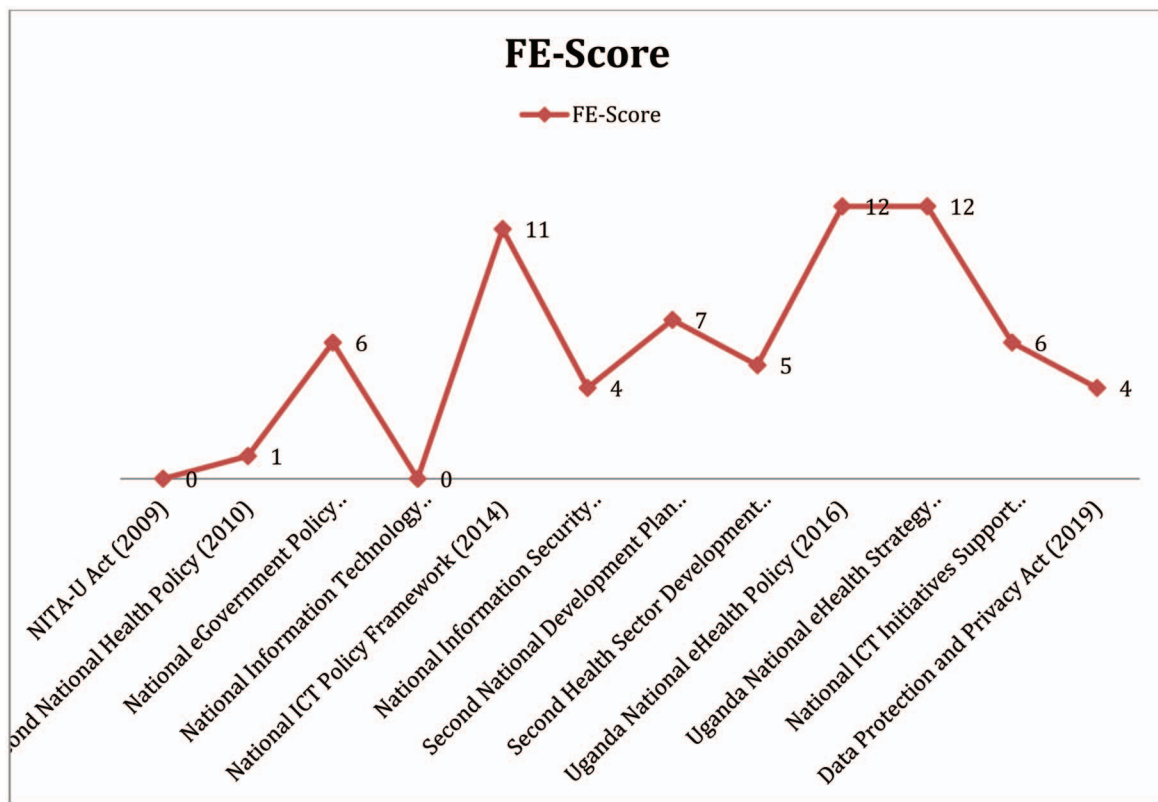


Figure 4. Evolution of FAIR Equivalency in the policy documents analysed (year of publication in parenthesis, 2009–2019).

Figure 4 shows the FE-Score against the year of publication of the documents. From this figure, it can be seen that the National eHealth Policy (2016) and the National eHealth Strategy (2017) have the highest FE-Scores, followed by the National ICT Policy Framework (2014). From Figure 4, it can be seen that FAIR Equivalency does not generally increase over time. Instead, the highest FAIR Equivalency is observed for the National eHealth Policy (2016) and the National eHealth Strategy (2017) (both FE-Score=12), followed by the National ICT Policy Framework (2014) (FE-Score=11). It should be noted that the three documents that exhibit the highest FAIR Equivalency form the core of the governance framework of Uganda’s eHealth sector and are the foundation of Uganda’s digital health/eHealth policy.

Table 3. FAIR Equivalency in policy documents analysed.

| Policy document                                 | FAIR Equivalency |      |    |         |      |      |       |    |        |      |        |       |        | FE-Score |       |      |
|---|------------------|------|----|---------|------|------|-------|----|--------|------|--------|-------|--------|----------|-------|------|
|   | F1               | F2   | F3 | F4      | A1   | A1.1 | A1.2  | A2 | I1     | I2   | I3     | R1    | R1.1   |          | R1.2  | R1.3 |
| NITA-U Act (2009)                               | 0                | 0    | 0  | 0       | 0    | 0    | 0     | 0  | 0      | 0    | 0      | 0     | 0      | 0        | 0     | 0    |
| Second National Health Policy (2010)            | 0                | 0    | 0  | 0       | 0    | 0    | 0     | 0  | 1      | 0    | 0      | 0     | 0      | 0        | 0     | 1    |
| National eGovernment Policy Framework (2011)    | 1                | 0    | 0  | 1       | 1    | 1    | 0     | 1  | 0      | 0    | 0      | 0     | 0      | 0        | 0     | 1    |
| National Information Technology Policy (2012)   | 0                | 0    | 0  | 0       | 0    | 0    | 0     | 0  | 0      | 0    | 0      | 0     | 0      | 0        | 0     | 0    |
| National ICT Policy Framework (2014)            | 1                | 1    | 0  | 0       | 1    | 1    | 0     | 1  | 1      | 1    | 0      | 1     | 1      | 1        | 1     | 11   |
| National Information Security Framework (2014)  | 0                | 0    | 0  | 0       | 1    | 0    | 1     | 0  | 0      | 0    | 0      | 0     | 0      | 0        | 0     | 2    |
| Second National Development Plan (2015)         | 1                | 0    | 0  | 0       | 1    | 1    | 0     | 1  | 0      | 1    | 0      | 1     | 0      | 0        | 0     | 6    |
| Second Health Sector Development Plan (2015)    | 0                | 0    | 0  | 0       | 1    | 0    | 0     | 0  | 1      | 0    | 1      | 1     | 0      | 0        | 1     | 5    |
| Uganda National eHealth Policy (2016)           | 1                | 1    | 0  | 1       | 1    | 1    | 0     | 1  | 0      | 1    | 0      | 1     | 0      | 1        | 1     | 11   |
| Uganda National eHealth Strategy (2017)         | 1                | 1    | 0  | 1       | 1    | 1    | 0     | 1  | 0      | 1    | 0      | 1     | 1      | 1        | 1     | 12   |
| National ICT Initiatives Support Program (2017) | 0                | 0    | 0  | 0       | 1    | 1    | 0     | 1  | 0      | 0    | 0      | 0     | 0      | 1        | 1     | 6    |
| Data Protection and Privacy Act (2019)          | 0                | 0    | 0  | 1       | 1    | 0    | 0     | 0  | 0      | 0    | 0      | 1     | 1      | 0        | 0     | 4    |
| Average   | 0.416667         | 0.25 | 0  | 0.33333 | 0.75 | 0.5  | 0.583 | 0  | 0.6667 | 0.08 | 0.3333 | 0.333 | 0.3333 | 0.333    | 0.333 | 0.5  |
| Percentage                                      | 41.7%            | 25%  | 0% | 33.3%   | 75%  | 50%  | 58.3% | 0% | 66.7%  | 8%   | 33.3%  | 33.3% | 33.3%  | 33.3%    | 33.3% | 50%  |
| Sum of FAIR-Equivalent (n)                      | 5                | 3    | 0  | 4       | 9    | 6    | 7     | 0  | 8      | 1    | 4      | 4     | 4      | 4        | 4     | 6    |

Source: Created by M. Basajja, 2021

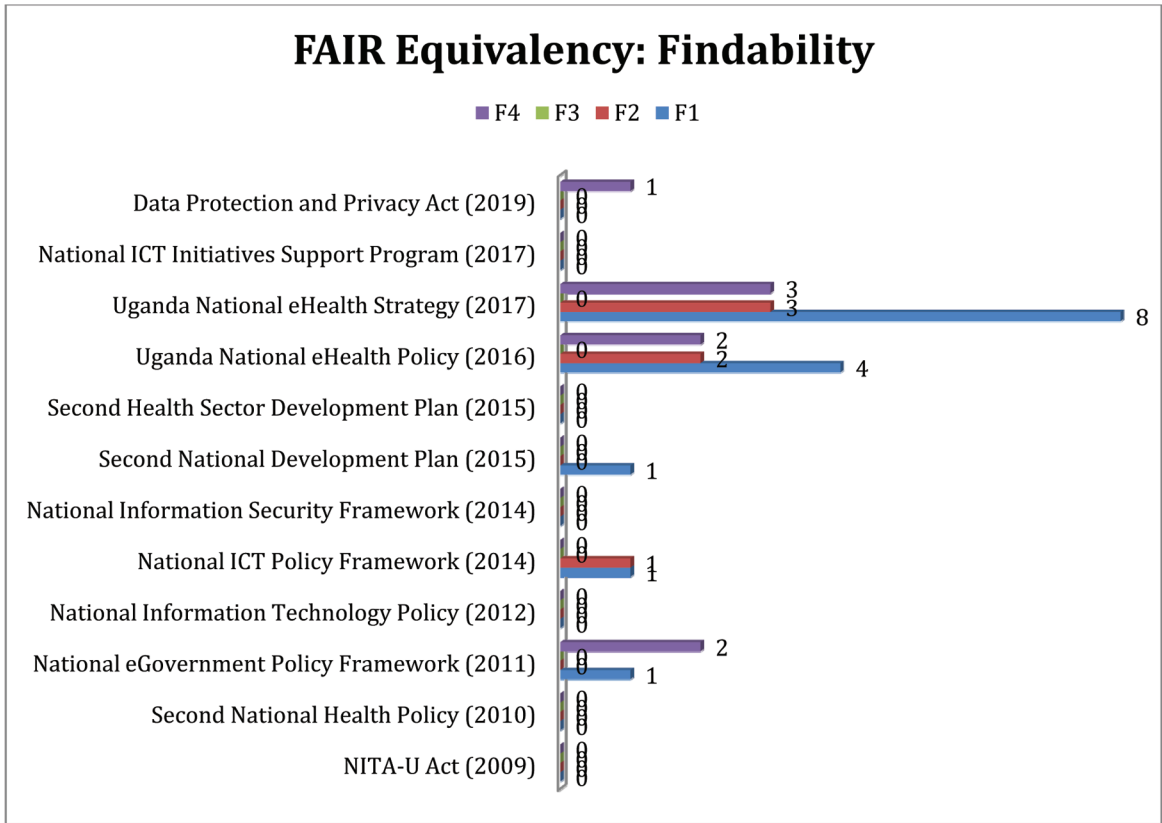


Figure 5a. Frequency of the mention of the equivalent of FAIR facets under 'Findability' (F1, F2, F3, F4) per policy document.

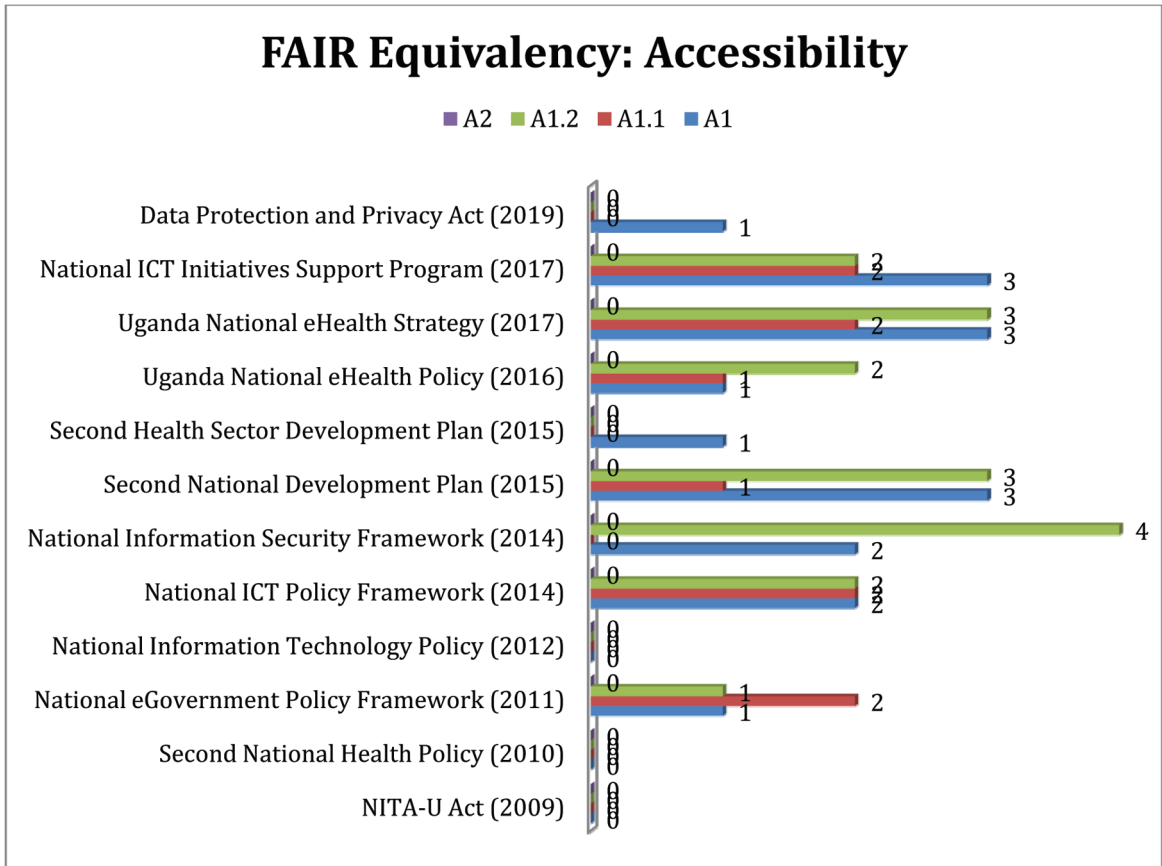
Source: Created by M. Basajja, 2021

#### 4. DISCUSSION

Even though none of the documents specifically mention the FAIR Guidelines, the use of FAIR Equivalent terminology shows that there is not a large gap between the position of the stakeholders that need to be convinced to accept the FAIR Guidelines and the foundation on which these principles are based. That is to say, cultural entropy is small, so it is not likely to be a major hindrance to the acceptance of the FAIR Guidelines.

##### 4.1 FAIR Equivalency

The results of the FAIR Equivalency analysis show that, across all of the policy documents, the facets for 'Accessibility' and 'Reusability' are mentioned most frequently (with a sum 22 and 18, respectively). 'Findability' and 'Interoperability' facets feature less often (with a sum of 12 and 13, respectively). The most mentioned FAIR Equivalent facets are A1 '(meta)data are retrievable by their identifier using a standardised



**Figure 5b.** Frequency of the mention of the equivalent of FAIR facets under ‘Accessibility’ (A1, A1.1, A1.2, A2) per policy document.

Source: Created by M. Basajja, 2021

communications protocol’ and I1 ‘(meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation’. While the least-mentioned FAIR Equivalent facets are F3, A2 and I2.

Regarding the least-mentioned FAIR Equivalent facets, Wilkinson and colleagues [1] described these facets as follows: F3—‘metadata clearly and explicitly include the identifier of the data it describes’; A2—‘metadata are accessible, even when the data are no longer available’; I2—‘meta(data) use vocabularies that follow FAIR Guidelines’. The reason why these FAIR Equivalent facets (F3, A2, and I2) are the least mentioned in the policy documents is because they are data-centric, i.e., they specifically deal with details about data and metadata, which is beyond the scope of the documents analysed, as they are policy-level documents and, therefore, do not explicitly mention such things. Therefore, it is only after the policies or guidelines in the documents have been implemented in a particular context that one can ascertain whether or not the particular implementation conforms with these facets.

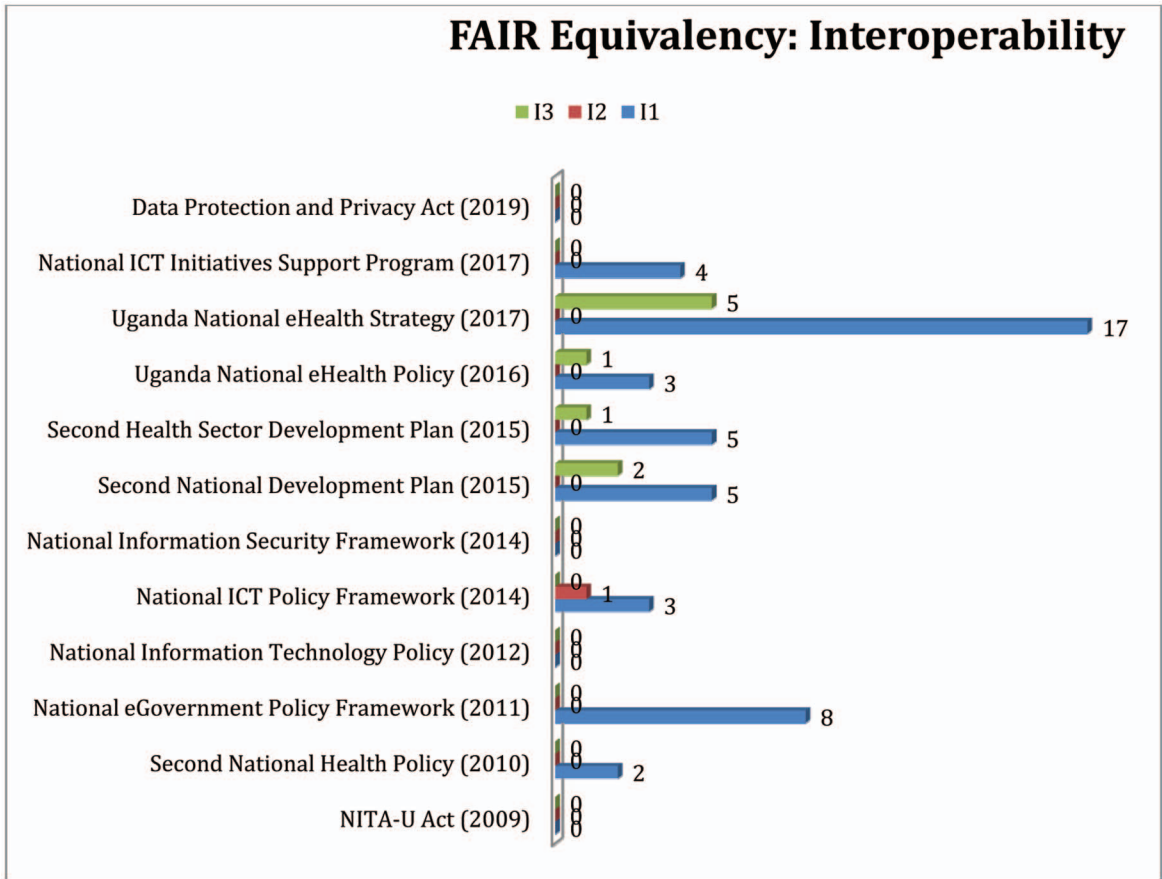


Figure 5c. Frequency of the mention of the equivalent of FAIR facets under ‘Interoperability’ (I1, I2, I3) per policy document.

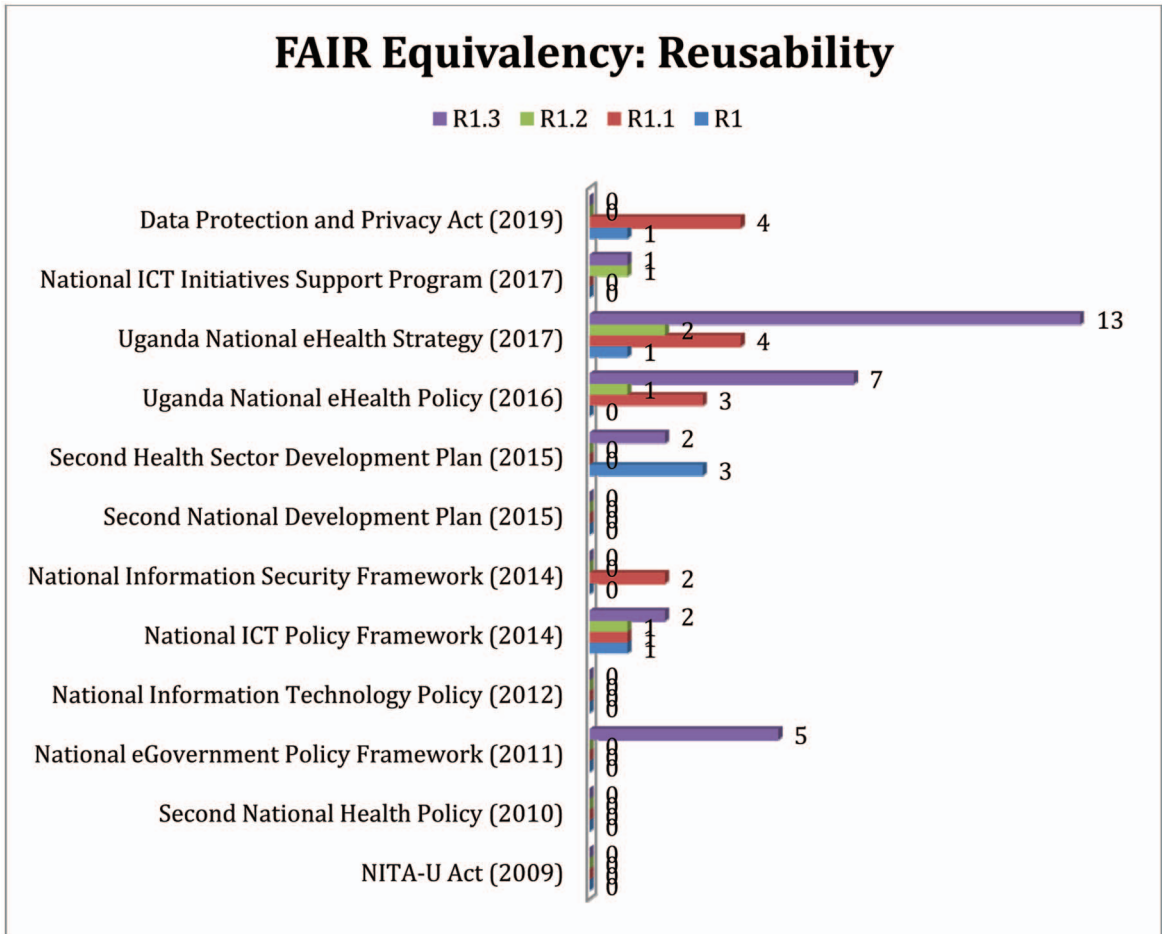
Source: Created by M. Basajja, 2021

#### 4.2 Facet A1

Facet A1 requires a standardised communications protocol, such as https or ftp, from which data and metadata can be retrieved by their identifier. Therefore, both human and automated users should be able to access the data/metadata by simply following a link. Facet A1 acknowledges that it may not always be possible to allow fully automated access to data, for example, in the case of highly-sensitive data. In such cases, providing contact details (such as an email address or telephone number) for the person who can discuss access to the data still renders the data FAIR [17].

Some of the examples of the mention of the equivalent of facet A1 in the policy documents are highlighted below. According to Uganda National eHealth Policy [14], the Ministry of Health has a Knowledge Management Portal—an online resource that integrates health and health-related information resources





**Figure 5d.** Frequency of the mention of the equivalent of FAIR facets under ‘Reusability’ (R1, R1.1, R1.2, R1.3) per policy document.

Source: Created by M. Basajja, 2021

from the Ministry of Health and beyond. This provides a single point of access to valuable information that facilitates evidence-based decision making [21]. A government web portal and local government websites were also identified among the key e-government services as facilities for displaying and disseminating government information and services on the Internet via the World Wide Web [22]. The National e-Government Policy Framework and the National ICT Policy Framework mention implementation of a government open data system to enable citizens to access government information, as one of the priority e-government applications identified in a survey [13, 22]. The National Development Plan (NDP) II Public Investment Plan also includes “Development of a Monitoring and Evaluation Web Portal with Database functionality to act as a one stop centre for information on monitoring and evaluation of Government Programmes”, as one of the NDP II pipeline projects [23]. In order to achieve NDP II objectives towards

ICT sector targets, one of the interventions is to establish regional information access centres and promote the use of ICT tools for trade, service delivery, and the exchange of information [23].

The Health Sector Development Plan (HSDP) II states that, during the plan period (2015/16–2019/20), special attention will be given to establishing a functional community information system by focusing on the following programme areas: a routine health management information system (HMIS), surveillance, vital statistics, research, health surveys and innovative eHealth solutions. Some of the key interventions in the routine HMIS area include: develop a National Health Information System Framework (NHISF) to create a reliable and accessible environment for managing health data [24].

### 4.3 Facet I1

Facet I1 is described as: ‘meta(data) use a formal, accessible, shared and broadly applicable language for knowledge representation’ [1]. Facet I1 requires use of commonly-used controlled vocabularies and ontologies, and a good data model with a well-defined framework to describe and structure data and metadata. The National eHealth Policy [14], National eHealth Strategy [15] and the National e-Government Policy Framework [22] mention the adoption and implementation of the Enterprise Architecture and Interoperability Framework for both e-government and eHealth implementations, which fulfils these requirements.

The National eHealth Strategy advocates for the development of an eHealth Enterprise Architecture and Interoperability Framework [25], with which all eHealth investments will have to conform and be certified. The National eHealth Strategy states that:

*Enterprise Architecture defines the structure for design and implementation of eHealth systems, linking the systems to be interoperable and using defined standards, so that health information and data from various sources can be linked and integrated to provide a better understanding of how the health sector is delivering overall health services. In so doing, eHealth as a whole experience reduced risk of fragmentation, less duplication of effort, and greater interoperability. [15]*

In addition, it calls for the implementation of a health information exchange and a shared electronic health record to allow for the sharing of information among health providers. This is the equivalent of the FAIR ‘Interoperability’ facet (I).

The Ministry of Health has adopted the District Health Information Software version 2 (DHIS2) as part of the national eHMIS and rolled it out up to the district level [26]. However, data from health facilities below the district level including community-based health data, data from vertical programmes, such as HIV/AIDS, tuberculosis and malaria programmes (which are run by non-governmental organisation or private health providers), and data from some referral hospitals (which are semi-autonomous) are not yet integrated into the national eHMIS/DHIS2 [15]. One of the strategic objectives of the National eHealth Strategy is to develop a community-based health information system and integrate information from related systems and vertical programmes into the national eHMIS [15]. This is in line with the ‘Interoperability’ principle of FAIR.

Various databases and information systems are mentioned in the National eHealth Policy and the National eHealth Strategy. These information systems have been developed and adopted to varying degrees, but are not yet integrated. Examples of these systems include: Human Resources for Health Information System (HRHIS), Clinical Information System (CIS), the national electronic Logistics and Supplies Management System (LSMIS), health facility systems, the provider and patient/client registry system, and so forth [14, 15]. Details about the planned integration of these systems can be found in Supplementary Material 4 Basajja, 2021.

### **4.4 Facet F1**

Perhaps the most important of the FAIR Guidelines is 'Findability', especially facet F1, which requires that data and metadata be assigned a globally unique and persistent identifier in order to be findable [1]. This is because without an identity that is unique, it is not easy for humans or machines to find a digital object, let alone determine if that object is reusable in their context. Therefore, the remaining three principles of FAIR (Accessibility, Interoperability and Reusability) are largely, or even entirely, hinged on 'Findability'.

Both the National eHealth Policy and National eHealth Strategy acknowledge that a unique health identifier is the cornerstone of most eHealth systems [14, 15]. The National eHealth Policy states that there is no unique identifier for health records and that health records are duplicated [14]. The National Identification and Population Databank Project established by the Government of Uganda contains citizens' bio-data including biometric features stored in a central national database [22]. The National Identification Project provides a unique identification number (the National Identification Number, or NIN) for every individual.

Both the National eHealth Policy and the National eHealth Strategy advocate for the reuse of existing initiatives, such as the NIN, as the unique health identifier for electronic medical records, electronic health records, and personal health records [14, 15]. Adoption of the NIN as the unique identifier for every patient/client and enforcing its use in the electronic medical records system is one of the strategic objectives of the National eHealth Strategy [15]. In addition to the patient/client unique identifier, there is also the health facility/health provider unique identifier that the Ministry of Health plans to adopt and enforce [15]. The NIN is the equivalent of the FAIR facet F1.

The Ministry of Health has adopted the Open Medical Records Systems (OpenMRS) as part of an effort to establish an electronic medical records system. OpenMRS is an open-source, electronic health record system supported by a large global network of developers and implementers and used in over 40 countries [27, 28]. The system will be used to electronically share an individual's medical record from one medical department to another. It will also help in tracking patients to address loss-to-follow-up of HIV patients, pregnant mothers who miss the four antenatal visits and tuberculosis patients as they receive their treatment. The Ministry planned to roll-out OpenMRS in 1,000 health facilities by the end of 2017 and adopt OpenMRS in more than 425 health facilities [29].

### **4.5 FAIR as a Solution to the Challenges in Uganda's eHealth Sector**

The FAIR Guidelines are firmly rooted in the premise that data from publicly-funded projects is a public good. These principles provide the necessary practices to make data accessible to the public so that the maximum benefit can be derived from them. However, the adoption of the idea of the FAIR Guidelines, as a precursor to the establishment of the Internet of FAIR Data and Services, depends on the opening of a policy window [4, 10].

But, how can a policy window be opened for the adoption of the FAIR Guidelines in Uganda's eHealth sector? Van Reisen and others note that the lack of adoption of the FAIR Guidelines in most research domains is partly because those domains do not see FAIR data stewardship as offering a solution to a problem that needs to be solved [4]. If the FAIR Guidelines are presented as a solution to the challenges faced by eHealth implementation in Uganda's eHealth sector, this may pave the way for the opening of a policy window for the adoption of the FAIR Guidelines.

Uganda's National eHealth Vision is structured around 13 eHealth pillars [14]. Acceptance of the FAIR Guidelines in Uganda's emerging eHealth sector is dependent on aligning the FAIR Guidelines with the National eHealth Vision. This can be done by exploring the barriers and opportunities in eHealth implementation and presenting the FAIR Guidelines as a workable solution. Eight eHealth pillars in which the FAIR Guidelines can help remove barriers to eHealth adoption/implementation were identified. These pillars also contain opportunities wherein FAIR can be accepted, adopted and subsequently implemented. These pillars include: 'Leadership and Governance', 'eHealth Enterprise Architecture', 'eHealth Services', 'Infrastructure', 'eHealth Information Assurance', 'Human Resources and Capacity Building', 'Change, Adoption, Business Process Re-engineering, and Transitioning', and 'Stakeholder Engagement'.

The 'eHealth Information Assurance' pillar relates to the security, confidentiality, privacy and integrity of electronic health data. For example, under this pillar, the Ministry of Health plans to review the National Information Security Framework and the Data Protection and Privacy Law to ensure that they address all the electronic health information security requirements in line with the existing regulatory environment, such as the Access to Information Act and international best-practices (e.g., the Global Health Information Privacy and Protection Statement [GHIPPS]) [15]. There is an opportunity for the FAIR Guidelines to be considered as part of this review, if they are presented as international best practice. The GO CHANGE pillar of FAIR [30] has a crucial role to play in this by leveraging/lobbying the relevant stakeholders (particularly those responsible for implementation of this pillar) to bring about alignment and synergy between the 'eHealth Information Assurance' pillar and the FAIR Guidelines. One of the strategic initiatives of the 'eHealth Information Assurance' pillar is "Develop and operationalize eHealth Information Security Guidelines and eHealth Information Privacy and Protection Guidelines, and monitor and enforce compliance to these guidelines by all stakeholders" [15].

Due to security and privacy concerns regarding personal data, these data are usually completely closed off, making them totally inaccessible to both humans and machines. The FAIR Guidelines can be presented as a solution in this case, because they ensure the publication of rich metadata to facilitate discovery, even

in the case of sensitive or personally-identifiable data, including clear rules regarding the process for accessing the data, which provides a high degree of 'FAIRness' even in the absence of FAIR publication of the data itself [1]. Therefore, by implementing the FAIR Guidelines, the 'eHealth Information Assurance' pillar can ensure that metadata is always public, even if the data are restricted or removed for privacy reasons, supporting the FAIR facets of 'Findability' and 'Accessibility'. In addition, regarding data anonymization/depersonalisation during aggregation due to privacy concerns, adopting FAIR can ensure that metadata is always public to enable 'Findability'. Another strategic initiative of the 'eHealth Information Assurance' pillar is "Develop data handling procedures and protocols to ensure consent/appropriate disclosure" [15]. In this vein, the FAIR Guideline of 'Reusability' requires meta(data) to be released with a clear and accessible data usage licence indicating dataset terms, who has the right to use the data, and how they can seek permission to use the data [1]. These principles can be built into the data handling procedures and protocols, thereby increasing the degree of FAIRness of the data.

Under the 'eHealth Services, Information Sharing and Data Management' pillar, the Ministry of Health's strategic objective is to establish an eHealth data, information and knowledge management, analysis and utilisation system. Under this strategic objective, there are the following strategic initiatives: develop data, information and knowledge sharing agreements that define the purposes for which health data may be shared between organisations; develop guidelines regarding data ownership/stewardship, data creation and collection, data quality, data audits and data analysis; create consistent national health data standards, definitions and dictionaries in accordance with the 'eHealth Enterprise Architecture'; develop a right-to-use policy that defines the purposes for which data can be used by health providers in the direct delivery of care to the patients/clients; and develop guidelines regarding the use of data analytics and health intelligence tools to access the vast amounts of digital health data, such as electronic medical records stored in clinical data repositories, as permitted by privacy regulations [15]. The FAIR Guidelines can be applied to all these areas, hence, this provides a perfect opportunity to adopt and implement them.

The electronic delivery of health services through mobile devices (mHealth) is another strategic objective of the Ministry of Health. Under this objective, the Ministry intends to develop and implement the required mHealth infrastructure used to develop mobile apps including the front-end, middleware (to connect the front-end with the back-end), and back-end (data access layer, server-side) [15]. Most digital health solutions use mobile devices to reach disadvantaged and underserved groups in the population. Therefore, if the FAIR Guidelines were adopted by the Ministry of Health in the development of mHealth infrastructure, such as application programming interfaces (APIs), these could subsequently be used by digital health providers to interface with the national HMIS, which would be an important step forward in the provision of FAIR Data and Services. Likewise the private sector, including mHealth app developers, can be engaged by the GO TRAIN and GO BUILD FAIR communities [31] on how to build mobile software that adheres to the FAIR Guidelines. Therefore, all the three pillars of GO FAIR—GO CHANGE, GO BUILD and GO TRAIN [31]—should put maximum effort into this area, given that it has important implications for the acceptance and adoption of the FAIR Guidelines in the digital health/eHealth sector and the establishment of the Internet of FAIR Data and Services [32].

Under the 'Human Resources and Capacity Building' eHealth pillar, the National eHealth Strategy acknowledges that a sufficient number of personnel with eHealth competencies and skills is a critical factor in the successful implementation of eHealth in Uganda. The Ministry intends to carry out a needs-assessment to evaluate the skills and competencies of its health professionals with the goal of developing and enforcing an eHealth curriculum framework to be followed by different training providers in developing and delivering health training. The Ministry also plans to: develop accredited courses/qualifications in eHealth (such as in health informatics); provide basic ICT training for health workers at all levels (continuous professional development) through e-learning and digital resources for offline learning; develop a national eHealth knowledge repository; and establish national eHealth centres of excellence [15]. This provides a unique opportunity for the adoption of FAIR Guidelines, which can be embedded in the eHealth curriculum, so that health professionals are not only equipped with eHealth skills, but also with knowledge of the FAIR Guidelines, which will be crucial in the building of the Internet of FAIR Data and Services. Towards this, the GO CHANGE and GO TRAIN pillars [31] will have to engage in serious consultations with relevant stakeholders to convince them to include the FAIR Guidelines in the eHealth curriculum and to participate in the training of the eHealth workforce. This training may be carried out at established eHealth centres of excellence. The author proposes that a regional (East Africa) FAIR Centre of Excellence be established by the Africa GO FAIR Implementation Network, in which professionals from various domains/backgrounds can receive instruction on the relevance and application of the FAIR Guidelines in their domain. Such a regional FAIR Centre of Excellence would be akin to the incubation/innovation hubs in the ICT sector, where the GO CHANGE, GO TRAIN and GO BUILD pillars [31] can come together and collaboratively perform their respective responsibilities. Such regional hubs have been used before to provide capacity building in new scientific fields. An example is the Biosciences Eastern and Central Africa, International Livestock Research Institute (Beca-ILRI) hub, which is located in Nairobi, Kenya [33, 34], where researchers from various sub-fields in the biosciences in the region can go to receive basic training in bioinformatics and genomics in order to create competencies in this new area. This regional FAIR Centre of Excellence can also give the FAIR Guidelines and GO FAIR movement much needed visibility.

Under the 'Infrastructure' eHealth pillar, the National eHealth Strategy calls for the utilisation of appropriate mature and emerging technologies to support eHealth development and enhance core eHealth services. Under this eHealth pillar, the Ministry of Health will assess the appropriateness of mature and emerging technologies for the support of health in the Ugandan situation, develop guidelines for such technologies, and continuously identify and review emerging technologies in healthcare to establish their applicability in the Ugandan healthcare environment. The National eHealth Strategy defines emerging technologies as new technologies that are currently developing, or will be developed, over the next 5 to 10 years, and which will substantially alter the business and social environment. Some of the examples of mature and emerging technologies mentioned are cloud computing, big data and open data, data analytics, smart systems, digital services and the Internet of things [15].

Van Reisen et al., explain that the motivation to listen to a message about the FAIR Guidelines is affected by the perceived usefulness of the message, and the objectives, opinions and beliefs the receiver has about the social process of data management [4]. Although the FAIR Guidelines are not, in themselves, a

technology, standard or specification [1], the fact that the Ministry of Health is invested in continuously identifying and reviewing technologies to support eHealth development and enhance eHealth services, and by virtue of the substantial impact that the FAIR Guidelines can have on the Ugandan healthcare environment (e.g., solving the problem of fragmentation of eHealth solutions) [5], there is an opportunity for the adoption of the FAIR Guidelines. Therefore, the social entrepreneurs and the GO CHANGE pillar of FAIR that are tasked with convincing and motivating potential users of the FAIR Guidelines to embrace them [4] should take advantage of this opportunity to create a policy window for the adoption of the FAIR Guidelines.

The 'Change, Adoption, Business Process Re-engineering and Transitioning' eHealth pillar is concerned with establishing a comprehensive eHealth transitioning strategy to take care of rapid changes in technology. Rapid technological changes are a challenge to eHealth implementation, because different organisations have different innovation cycles, hence, adopt different technologies, which are usually incompatible [15]. This pillar seeks to manage the rapid changes in technology during eHealth implementation by enforcing adherence to the eHealth 'Enterprise Architecture', which ensures standardisation and interoperability, such that any new technologies can integrate with existing ones [15]. This is partly in line with the FAIR Guidelines, so there is an opportunity to fully align and conform this objective to the FAIR Guidelines. Moreover, the Ministry of Health Resource Centre (which is tasked with implementation of this eHealth pillar) is responsible for "keeping abreast with current trends and forecasting changes early enough to enable review of plans" [15]. The GO CHANGE pillar may, therefore, liaise with the Ministry of Health Resource Centre to motivate and encourage adoption of the FAIR Guidelines in this pillar.

The 'Stakeholder Engagement' eHealth pillar has the following roles: engage all eHealth stakeholders at the national, regional and international levels; carry-out mass campaigns and training to create awareness of eHealth services and applications among target groups; and establish a framework for measuring the effectiveness of engagement and awareness campaigns [15]. Here, there is an opportunity for the FAIR Guidelines to be included alongside eHealth during stakeholder engagement and awareness creation so that the mass campaigns advocating for adoption of eHealth also call for the adoption of the FAIR Guidelines.

Another way in which the policy window for the adoption of the FAIR Guidelines can be opened is if they are established as part of international best practices for good data management and stewardship. Many guidelines, protocols, procedures and regulations that have been established as international best practices are quickly adopted, because policymakers and stakeholders always carry out benchmarking and extensive consultations when establishing a new area (for example, eHealth). These stakeholders always seek to align with the international best practices when developing or reviewing guidelines, regulations, protocols and procedures. For example, if the FAIR Guidelines were to be established by the World Health Organization as part of international best practices in eHealth implementation, they would easily be adopted by all downstream institutions that seek to align their eHealth vision with international best practices. For example, Uganda adopted the eHealth Enterprise Architecture and Interoperability Framework to guide the implementation of its eHealth strategy after carrying out a benchmarking/review of eHealth experiences both internationally (Australia, England, Scotland, Northern Ireland, Denmark, Cuba, Philippines and Canada) and regionally (South Africa, Nigeria, Rwanda, Tanzania, Kenya and Ghana). The output from

this review was the definition of the international best practice/criteria for the optimum eHealth governance and eHealth implementation solution for Uganda [14].

### **5. CONCLUSION**

Implementing the FAIR Guidelines in the digital health/eHealth sector in Africa has the potential to solve problems—such as the lack of sustainability of digital health initiatives and fragmentation and lack of integration of health service solutions—as long as they are adopted and implemented with contextual awareness. The general objective of this study was to assess the governance framework for digital health/eHealth policy in Uganda and explore the possibility of a policy window opening for the FAIR Guidelines to be adopted and implemented in Uganda's eHealth sector. The key policy documents relating to information, communication and technology (ICT) and health that are pivotal to the emerging eHealth sector were identified. The 12 policy documents obtained were then analysed using a comprehensive coding and labelling approach that employs a binary system using keywords and phrases to indicate whether or not the documents mention the FAIR Guidelines (that data be Findable, Accessible, Interoperable and Reusable), or the equivalent of 15 FAIR sub-criteria/facets, in order to determine the level of FAIR Equivalency. A FAIR Equivalency Score (FE-Score), which is the sum of the 15 FAIR sub-criteria/facets, was then obtained for each policy document. The analysis found that although none of the documents mention the FAIR Guidelines, 10 out of the 12 documents (83%) mention the equivalent of the FAIR Guidelines. The FE-Score, which was devised for this study as an aggregate score of the mention of the equivalent of FAIR facets in the policy documents, revealed that Uganda's National eHealth Policy, National eHealth Strategy and National ICT Policy Framework have the highest FE-Scores. The higher the FE-Score, the more in sync the policy document is with the FAIR Guidelines. These three documents are the most recently drafted of the 12 selected policy documents.

Whereas the FAIR Guidelines were not mentioned in any of the policy documents in Uganda's eHealth sector, 83% of the documents mentioned FAIR Equivalency efforts, such as the adoption of the National Identification Number as a unique identifier in Uganda's national eHMIS ('Findability'), planned/ongoing integration of the various information systems ('Interoperability'), and alignment of various projects with international best practice/standards ('Reusability'). These findings indicate that there is not a large gap between the position of the stakeholders that need to be convinced to accept the FAIR Guidelines and the foundation on which the FAIR Guidelines are based. Therefore, it can be concluded that favourable conditions exist for a push to adopt and implement the FAIR Guidelines in Uganda's eHealth sector.

### **6. LIMITATIONS OF THIS STUDY**

Efforts were made to obtain all published documents relevant to the research objectives by searching the websites of relevant NGOs and government institutions. Key personnel in the designated ministries, departments and agencies were also contacted and formal requests for the relevant documents submitted. However, two documents that were considered relevant to this study were not included, because they were not available online and were not provided upon request. Regarding scope, this research article focused



on national-level documents published by the Government of Uganda (policies/policy frameworks, strategies, plans, legislation and programmes) in order to obtain the governance overview required by the research objective. Annual health sector performance reports, evaluation reports, survey reports and programme reports were not included.

### **ACKNOWLEDGEMENTS**

We would like to thank Misha Stocker for managing and coordinating this Special Issue (Volume 4) and Susan Sellars for copyediting and proofreading. We would also like to acknowledge VODAN-Africa, the Philips Foundation, the Dutch Development Bank FMO, CORDAID, and the GO FAIR Foundation for supporting this research.

### **AUTHOR CONTRIBUTIONS**

Mariam Basajja (mariam.basajja@gmail.com, 0000-0001-7710-8843): conception and design of the work, data collection, data analysis and interpretation, drafting of the article, critical revision of the article, and approval of the final version to be published. Mirjam Van Reisen (mirjamvanreisen@gmail.com, 0000-0003-0627-8014): conception and design of the work, critical revision of the draft and approval of the final version to be published. Francisca Oladipo (francisca.oladipo@kiu.ac.ug, 0000-0003-0584-9145): Approval of the final version to be published.

### **CONFLICT OF INTEREST**

All of the authors declare they have no competing interests.

### **ETHICS STATEMENT**

Tilburg University, Research Ethics and Data Management Committee of Tilburg School of Humanities and Digital Sciences REDC#2020/013, June 1, 2020-May 31, 2024 on Social Dynamics of Digital Innovation in remote non-western communities.

The study was approved by the Kampala International University Research Ethics Committee. Permission to conduct interviews in the health facilities was also obtained from the Ugandan Ministry of Health, district local government authorities and the respective district health officers. All participants provided voluntary informed consent before each interview. The privacy of the participants was ensured by conducting the interviews in private and not including identifiable information. Individual autonomy to participate in the study was guaranteed, as participants were free to decline to participate. All who consented to participate were informed about their freedom to withdraw from the study at any time. No participant withdrew from the study. Permission to tape record the data was similarly obtained. All the audio recorded material and transcripts were safely stored by the lead author (Mariam Basajja).

## REFERENCES

- [1] Wilkinson, M.D., Dumontier, M., Aalbersberg, I.J., Appleton, G., Axton, M., Baak, A., et al.: The FAIR Guiding Principles for scientific data management and stewardship. *Scientific Data* 3(1), 1–9 (2016)
- [2] Dutch Techcentre for Life Sciences: The FAIR Data Principles explained [Online]. Available at: <https://www.dtls.nl/fair-data/fair-principles-explained/>. Accessed 30 April 2020
- [3] Mons, B.: Data stewardship for open science. Implementing FAIR Principles (1st edition). CRC Press, Boca Raton (2018). Available at: <https://www.routledge.com/Data-Stewardship-for-Open-Science-Implementing-FAIR-Principles/Mons/p/book/9780815348184>. Accessed 11 February 2021
- [4] Van Reisen, M., Stokmans, M., Basajja, M., Ong'ayo, A.O., Kirkpatrick, C., Mons, B.: Towards the tipping point for FAIR implementation. *Data Intelligence* 2(1–2), 264–275 (2020)
- [5] Van Reisen, M., Stokmans, M., Mawere, M., Basajja, M., Ong'ayo, A.O., Nakazibwe, P., Kirkpatrick, C., Chindoza, K.: FAIR Practices in Africa. *Data Intelligence* 2(1–2), 246–256 (2020)
- [6] East African Health Research Commission: Digital Regional East African Community Health Initiative Roadmap. EAHRC (2017). Available at: [https://www.eahealth.org/sites/www.eahealth.org/files/content/attachments/2019-02-06/Digital-REACH-Initiative-Roadmap\\_20171205\\_custom\\_size\\_0.pdf](https://www.eahealth.org/sites/www.eahealth.org/files/content/attachments/2019-02-06/Digital-REACH-Initiative-Roadmap_20171205_custom_size_0.pdf). Accessed 11 February 2021
- [7] GO FAIR: IN-Africa [Online]. Available at: <https://www.go-fair.org/implementation-networks/overview/in-africa/>. Accessed 1 May 2020
- [8] GO FAIR: Virus Outbreak Data Network (VODAN) [Online]. Available at: <https://www.go-fair.org/implementation-networks/overview/vodan/>. Accessed 13 May 2020
- [9] Kampala International University: Data Science through GO FAIR in Africa: A new generation Internet of data & services [Online]. Kampala International University (n.d.). Available at: <https://www.kiu.ac.ug/engagements.php?i=data-science-through-go-fair-in-africa-a-new-generation-internet-of-data-and-services>. Accessed 1 May 2020
- [10] Kingdon, J.W.: *Agendas, alternatives, and public policies*. Harper Collins Publishers, New York (1984)
- [11] Van Reisen, M.: *Window of opportunity: EU development cooperation after the end of the Cold War*. Africa World Press Ltd, Trenton and Europe External Policy Advisors, Brussels (2009)
- [12] Tashobya, C. K, Ssengooba, F., Oliveira Cruz, V. (eds): *Health systems reforms in Uganda: Processes and outputs*. Health Systems Development Programme, London School of Hygiene & Tropical Medicine (2006). Available at: [https://assets.publishing.service.gov.uk/media/57a08c2940f0b652dd00115a/Uganda\\_book.pdf](https://assets.publishing.service.gov.uk/media/57a08c2940f0b652dd00115a/Uganda_book.pdf). Accessed 11 February 2021
- [13] Ministry of Information and Communications Technology: *National Information and Communications Technology Policy for Uganda*. Ministry of Information and Communications Technology, Uganda (2014). Available at: [https://ict.go.ug/wp-content/uploads/2018/11/ICT\\_Policy\\_2014.pdf](https://ict.go.ug/wp-content/uploads/2018/11/ICT_Policy_2014.pdf). Accessed 11 February 2021
- [14] Ministry of Health: *Uganda National EHealth Policy*. Ministry of Health, Uganda (2016). Available at: <http://library.health.go.ug/download/file/fid/517>. Accessed 11 February 2021
- [15] Ministry of Health: *Uganda National EHealth Strategy*. Ministry of Health, Uganda (2017). Available at: [http://health.go.ug/sites/default/files/National\\_e\\_Health\\_Strategy\\_0.pdf](http://health.go.ug/sites/default/files/National_e_Health_Strategy_0.pdf). Accessed 11 February 2021
- [16] Mutatina, B., Basaza, R., Obuku, E., Lavis, J.N., Sewankambo, N.: Identifying and characterising health policy and system-relevant documents in Uganda: A scoping review to develop a framework for the development of a one-stop shop. *Health Research Policy and Systems* 15(1), 7 (2017)
- [17] GO FAIR: FAIR Principles [Online]. Available at: <https://www.go-fair.org/fair-principles/>. Accessed 30 April 2020

- [18] Ranney, M.L., Meisel, Z.F., Choo, E.K., Garro, A.C., Sasson, C., Morrow Guthrie, K.: Interview-based qualitative research in emergency care part II: Data collection, analysis and results reporting. *Academic Emergency Medicine* 22(9), 1103–1112 (2015)
- [19] Gale, N.K., Heath, G., Cameron, E., Rashid, S., Redwood, S.: Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology* 13(1), 117 (2013)
- [20] Wong, L.: Data analysis in qualitative research: A brief guide to using Nvivo. *Malaysian Family Physician* 3(1), 14 (2008)
- [21] Ministry of Health: Knowledge management portal. Republic of Uganda. Available at: <http://library.health.go.ug/publications/health-information-systems/ministry-health-knowledge-management-portal-website-user>. Accessed 30 April 2020
- [22] Ministry of Information and Communications Technology: National E-Government Policy Framework. Republic of Uganda (2011). Available at: [http://www.ict.go.ug/wp-content/uploads/2018/06/National\\_E-Government\\_Policy\\_Framework\\_2011-2.pdf](http://www.ict.go.ug/wp-content/uploads/2018/06/National_E-Government_Policy_Framework_2011-2.pdf). Accessed 11 February 2021
- [23] National Planning Authority: Second National Development Plan. Republic of Uganda (2015). Available at: <http://npa.go.ug/wp-content/uploads/NDPII-Final.pdf>. Accessed 11 February 2021
- [24] Ministry of Health: Second Health Sector Development Plan. Republic of Uganda (2015). Available at: [https://health.go.ug/sites/default/files/Health%20Sector%20Development%20Plan%202015-16\\_2019-20.pdf](https://health.go.ug/sites/default/files/Health%20Sector%20Development%20Plan%202015-16_2019-20.pdf). Accessed 11 February 2021
- [25] Adenuga, O.A., Kekwaletswe, R.M., Coleman, A.: eHealth integration and interoperability issues: Towards a solution through enterprise architecture. *Health Information Science and Systems* 3(1) (2015)
- [26] Kiberu, V.M., Matovu, J.K., Makumbi, F., Kyoziira, C., Mukooyo, E., Wanyenze, R.K.: Strengthening district-based health reporting through the district health management information software system: The Ugandan experience. *BMC Medical Informatics and Decision Making* 14(1), 40 (2014)
- [27] Wolfe, B.A., Mamlin, B.W., Biondich, P.G., et al.: The OpenMRS system: Collaborating toward an open source EMR for developing countries. *AMIA Annual Symposium Proceedings 2006*, 1146 (2006)
- [28] Mohammed-Rajput, N.A., Smith, D.C., Mamlin, B., Biondich, P., Doebbeling, B.N.: OpenMRS, a global medical records system collaborative: Factors influencing successful implementation. *AMIA Annual Symposium Proceedings 2011*, 960–968 (2011)
- [29] Daily Monitor: Government embraces electronic medical records system [Online]. *Daily Monitor* (December 2016). Available at: <https://www.monitor.co.ug/News/National/Government-embraces-electronic-medical-records-system/688334-3481034-7qje6ez/index.html>. Accessed 30 April 2020
- [30] GO FAIR: GO CHANGE [Online]. (n.d.). Available at: <https://www.go-fair.org/go-fair-initiative/go-change/>. Accessed 1 May 2020
- [31] GO FAIR: GO FAIR Initiative [Online]. (n.d.). Available at: <https://www.go-fair.org/go-fair-initiative/>. Accessed 1 May 2020
- [32] Van Reisen, M., Oladipo, F., Stokmans, M., Mpezamihgo, M., Folorunso, S., Schultes, E., et al.: Design of a FAIR digital data health infrastructure in Africa for COVID-19 reporting and research. *Advanced Genetics* 2(2) (2021). doi: 10.1002/ggn2.10050
- [33] Biosciences Eastern and Central Africa: About the BecA-ILRI hub [Online]. *Africa Hub* (n.d.). Available at: <http://hub.africabiosciences.org/aboutbeca>. Accessed 1 May 2020
- [34] Biosciences Africa: Build, empower and amplify: Bioinformatics for agri-research in Africa. *Africa Hub* (28 August 2018). Available at: <https://hub.africabiosciences.org/media-center/news/581-build-empower-and-amplify-bioinformatics-for-agri-research-in-africa>. Accessed 1 May 2020